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# “I Can’t Go to School and Leave Her in So Much Pain”: Educational Shortfalls Among Adolescent ‘Young Carers’ in the South African AIDS Epidemic

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## Abstract

“I go to the hospital with my mother when she is sick. I can’t go to school and leave her in so much pain. I won’t concentrate.” Millions of adolescents live with AIDS-affected parents or primary caregivers. Little is known about educational impacts of living in an AIDS-affected home, or of acting as a “young carer” in the context of AIDS. This study combined qualitative and quantitative methods to determine educational impacts of household AIDS-sickness and other-sickness. Six hundred and fifty-nine adolescents (aged 10-20) were interviewed in high-poverty areas of urban and rural South Africa. Qualitative findings identified three major themes of missing school, being hungry at school, and concentration problems due to worry about the sick person. In quantitative analyses, living in an AIDS-affected home predicted all these three outcomes ( $p < .001$ ) compared to homes affected by other sickness and to healthy homes, and independent of sociodemographic cofactors. This

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study demonstrates that familial AIDS-sickness is associated with negative educational impacts for adolescents. It is important that policies are developed to support young people in these circumstances to continue with their education.

### **Keywords**

education/school, family relationships, young carers, HIV/AIDS, South Africa

### **Introduction**

In the developed world, there has been increasing recognition of a hidden group of adolescents: those who are “young carers” to a sick or disabled parent. Becker (2000) defines young carers as children and adolescents who take on “substantial and significant tasks” with “responsibility that would normally be associated with an adult” when someone, typically a relative in the household, becomes unwell. Research suggests that these young people experience disadvantage in educational access. Dearden & Becker (2002) reviewed U.K. studies of young carers and found high levels of school absence, tiredness, anxiety, poor attainment, and behavioral problems. In Australia, Gray, McArthur et al. (2006) conducted semistructured qualitative interviews with 55 young carers in support groups and found high value placed on education but problems with school attendance, classroom participation, and academic achievement. In the United States, a study of 11,029 students found that 67% of young carers reported that their academic performance had suffered, with 24% reporting difficulty concentrating and 13% missing school or after-school activities (Siskowski, 2006).

There is little known research on young carers in developing world settings such as sub-Saharan Africa, where large numbers of adolescents are likely to provide care to adults living with illness such as AIDS. South Africa alone has 5.7 million HIV+ people, more than any other country in the world, with 29% of antenatal clinic attendees infected in 2008 (Department of Health, 2009). As of 2009, the national antiretroviral rollout reached only 22% of those diagnosed with AIDS illness (Aarif Adam & Johnson, 2009), leaving millions of parents untreated and with chronic and worsening opportunistic infections. In addition to HIV/AIDS, South Africa faces a high burden of other diseases, such as diabetes and hypertension. The public health system, still coping with an apartheid legacy of underfunding and skills shortage, lacks capacity for providing care to those in need. As a result, many people living with AIDS and other illnesses are cared for in the home. Throughout

sub-Saharan Africa, policies have encouraged “Home-Based Care,” both as a means to reduce the burden on the public health system and with the aim that patients experience more dignified and community-based palliative care. Qualitative and anecdotal evidence suggests that young people are often the providers of medical and intimate care for sick relatives and frequently assume responsibilities for domestic work and sibling care (Bauman et al., 2006; Robson, 2000).

Although there is no systematic research of the educational outcomes of young carers in sub-Saharan Africa (Becker, 2007) small-scale studies provide preliminary indications of challenges. Robson et al. (2000) interviewed 9 young carers of AIDS-sick adults in Zimbabwe and found that 6 had ceased school attendance. Bauman et al. (2006) conducted research with 50 young carers in Zimbabwe who lived with an HIV+ parent, and found 67% reported interference with homework. In Kenya, Skovdal, Ogutu, Aoro, and Campbell (2009) used qualitative photovoice techniques with 48 children in AIDS-sick households. They found that, while all children struggled with school attendance and performance, they also reported that education gave a sense of normality and that teachers were sympathetic. Some continued to succeed despite missing large sections of school, but long-term negative educational impacts were “the greatest concern for many of these children.” A large, quantitative study in urban South Africa examined impacts on children of any sickness in the household (Gray, Van Niekerk, et al., 2006). Children in sick households were less likely to have school fees paid ( $p < .001$ ), were more likely to be absent from school ( $p < .001$ ), and to be unsupervised while doing homework ( $p < .001$ ).

The available evidence has key limitations. The lack of comparison groups consisting of respondents with healthy and other-sick primary caregivers means that it is not possible to assess whether this pattern of educational outcomes is associated specifically with parental AIDS illness. Indeed, because of high prevalence of other chronic and infectious illnesses in sub-Saharan Africa, it is important to determine whether young carers of AIDS-unwell adults show different levels of problem outcomes compared with young carers of adults who have other forms of illness. Additionally, the available evidence suggests that the burden of responsibility for young people in AIDS-affected homes rises with the age of the young person. Despite this, few studies focus on adolescents and young people who may be the most affected by familial AIDS-sickness.

In summary, there remains a clear need for research to investigate educational impacts among young carers in the context of South Africa’s HIV/AIDS epidemic, to distinguish outcomes for adolescents living with AIDS-sick versus

other-sick adults, and to examine potential cofactors that may be associated with educational access for young carers. As Skovdal et al. (2009) highlight, it is important not to assume that young people are universally “victims of damaging circumstances,” but to allow adolescents’ own voices to determine potentially either positive or negative impacts. However, if educational shortfalls among young carers in South Africa are found, then social policies and interventions are necessary to ameliorate these problems.

This study had two primary research questions.

*Research Question 1:* What impacts on their education do adolescents living in sick homes and healthy homes identify?

*Research Question 2:* Are educational outcomes associated with adult illness (AIDS-related or other-sickness), sociodemographic factors, and extent of young people’s work?

We developed a two-stage study to examine these questions among a sample of adolescents in sick and healthy homes in South Africa. First, we used in-depth, open-ended qualitative interviews to allow participants to identify and define the impacts of caring responsibilities on their education. Second, we quantitatively assessed the extent of these impacts, compared participants according to whether they cared for an adult with AIDS illness, other illness, or lived in a healthy home, and examined potential cofactors of caring such as age, gender, and extent of adolescent’s care work. A phenomenological qualitative approach was essential for two reasons. First, because there is no known research in South Africa on which to make assumptions about educational experiences of adolescents living in families affected by sickness, and second, because impacts of home life on education are often subjectively experienced.

The study used the overarching framework of Bronfenbrenner’s ecological theory (Bronfenbrenner, 1979). In this, outcomes for young people (such as education) are affected by a range of coexisting spheres of individual, family, school, access to services such as health care, and wider social structures. Where risks are experienced in multiple spheres, youth outcomes are likely to be seriously compromised. Equally, though, support or success in one sphere can ameliorate or buffer the negative impacts of risk in another.

## **Method**

This study was developed in collaboration between researchers, adolescents living with sick carers, the South African government, and NGOs. Interview

protocols were designed with the help of a “Teen Advisory Group” of 11 Young Carers, who provided advice on developing an age-appropriate and engaging instrument to understand experiences among adolescents caring for an unwell adult. In addition, regular consultative meetings were held with the National Departments of Social Development, Basic Education and Health, and NGOs such as the Regional Psychosocial Support Initiative (REPSSI) and Cape Town Child Welfare. The resulting protocol was aimed to be accessible to adolescent participants and used a graphically intensive comic-style format, based around characters named “Nelson” and “Winnie.”

**Participant recruitment.** The sampling frame included all 20 rural communities or urban townships identified as the most deprived in the Western Cape by the Provincial Indices of Multiple Deprivation (Noble et al., 2005). All areas were isiXhosa speaking, and characterized by high HIV prevalence (e.g. 32% of antenatal attendees HIV+ in urban Khayelitsha, 34% in rural Grabouw) and AIDS-related stigma. Participants were recruited through both door-to-door community sampling (20 communities) and schools (2 per community). Non-school-based sampling was essential in order to ensure inclusion of young people who were not attending school or who had left education in order to provide care. Adolescents self-identified as living with a chronically ill (i.e., for more than 1 month) caregiver and were then matched with adolescents living in healthy households by age, gender, and close neighborhood. In total, 659 young people, aged 10 to 20, were interviewed in urban (56%) and rural (44%) areas of the Western Cape, South Africa. Due to lack of population information, this study aimed for a large sample size and maximum variation sampling (Patton, 2002); that is, to include children and young people from a wide range of areas, with different types of familial sickness, in both urban and rural areas. It also included older adolescents and young adults, as in South Africa many young people continue school education beyond 18 years.

**Ethics and consent.** Ethical approval for the study was given by Oxford University, the University of Cape Town, and the Western Cape Education Department. Full informed consent was obtained from both participants and their caregivers. Consent forms were read aloud by interviewers to ensure understanding in contexts of low literacy. Interviewers were extensively trained in responding to adolescents’ distress or difficulties. Any participant who reported abuse or circumstances suggesting significant harm during the study was referred to social services, counseling, or relevant organizations and helplines. One adolescent declined to participate in the study.

**Data collection.** All interviews took place face-to-face and aimed to ensure privacy for participants. Interviewers were female, isiXhosa-speaking social workers and community health workers. In order to increase consistency across

Time	What do you do?	How do you feel?
6am-8am	I clean my mother's bed (20 mins), I fetch and boil water for her to drink her treatment (30 mins). I wake up my siblings (20 mins), I cook breakfast for everyone (20 mins). I get ready for school (30 mins)	I feel good to help my family. Sometimes I feel sad.
8am-8.30am	I take my siblings to crèche (30 mins) and then I go to school. Sometimes I miss school if I have to take her to the clinic.	I can't concentrate at school. I am worried.
2pm	I get back from school. I sweep the floor (20 mins). I go to the shop to buy food (25 mins). I wash clothes for everyone and pack the dry clothes from yesterday in the wardrobe (1 hour)	I am proud of myself or helping them
5pm	I cook supper for the family (60 mins but I can do my homework while it is cooking)	[Nothing written]
8pm	I give the sick people their treatment (30 mins). I wash up from dinner (20 mins) and then I go to bed.	I am worried about them

**Figure 1.** Example of adolescent participant's daily timetable (girl, 16, urban)

interviewers, a uniform interview protocol was used, and daily meetings were held to discuss techniques and issues. In order to avoid any potential stigmatization of research participants, the study was introduced as investigating “the care and help that families give to one another.” HIV/AIDS was not mentioned in any of the research materials. The protocol utilized both qualitative and quantitative sections. Open-ended questions and probes addressed daily housework and educational factors among participants. In order to determine the amount of care work that participants were doing, young people completed a “daily timetable” in which they described all of their activities during a typical weekday, from waking to sleeping; an hourly chart was provided to cue daily activities and estimate the amount of time per activity (see Figure 1). This was based on tools used by Evans and Becker with AIDS-affected young people in Tanzania (Evans & Becker, 2010). To assess educational outcomes, participants responded to open-ended questions, aiming to allow in-depth responses of participants' experiences and perceptions: “How are things—good and bad—at school?” and, for participants who stated their caregiver had a chronic illness, “Have there been any changes at school since your caregiver got sick?”

Aiming at participatory and empowering methods, participants chose whether to write or draw responses, or else elected for the interviewer to write their responses. Where participants drew responses (such as drawing themselves administering TB medication to a parent), the interviewer would ask the adolescent to explain what was happening in the picture, and would write this alongside the drawing. Participants also chose between interviews in isiXhosa or English. Audio-recording of all qualitative sections of interviews was not possible due to safety risks of audio equipment in high-crime areas, but a subset of interviews were recorded and checked against written questionnaires for accuracy and sensitivity.

Interview protocols also included standard measures of parental morbidity and mortality and young people's sociodemographic characteristics. To categorize participants into one of our three comparison groups, we first assessed whether they lived with an adult caregiver who had any chronic illness. Participants who reported at least one chronically ill adult in the household were further categorized as living with (a) AIDS-sick caregivers or (b) other-sick caregivers; participants who reported no chronically ill adults in the household were categorized as living in (c) "healthy homes." To classify participants as having AIDS-sick versus other-sick caregivers, we administered an adapted version of the "verbal autopsy" measure (Lopman et al., 2006). This has been validated in South Africa and other countries with low levels of HIV testing to classify AIDS illness (Hosegood, Vanneste, & Timaeus, 2004) and shown to have good sensitivity and specificity in determining AIDS-related death. For this study, determination of AIDS-related caregiver sickness required identification of three or more AIDS-defining illnesses; for example, Kaposi's sarcoma, HIV-wasting syndrome, and oral candidiasis (Cluver, Gardner, & Operario, 2007). Where diagnoses were in doubt, symptoms were reviewed by two independent medical practitioners. Based on this measure, 212 participants were categorized as having AIDS-sick caregivers, 140 participants having other-sick caregivers, and 247 participants living in healthy homes; 60 participants who reported having a chronically sick caregiver at home were excluded from analyses due to an inability to determine cause of illness (i.e. tuberculosis with no other AIDS-defining illnesses). Additional standard questions, based on the South African Census (Statistics South Africa, 2001) assessed age, gender, household composition, and urban/rural area.

**Data analysis.** Data analysis took place in two stages, described in detail below. In brief, open-ended qualitative data (both writing and descriptions of drawings) were analyzed to illuminate the subjective experiences of adolescents and to identify normative and nonnormative themes with regard to



education and caring responsibilities. Subsequently, those themes that were identified by sufficient numbers of respondents to include in regression analyses were examined quantitatively to identify relationships of educational outcomes to household sickness, sociodemographic factors, and extent of young person's work.

*Qualitative analyses.* Interviews were coded and analyzed using thematic content analysis (Weber, 1990) and followed analysis methods used by Skovdal et al (2009), which allowed an explicitly phenomenological approach to the experiences of young people caring for sick relatives. An initial detailed reading and rereading of responses enabled coding of topics raised by participants, identifying commonalities that emerged from the data rather than a priori categories (Step 1). Themes were developed from the coded text (Step 2) and clustered into organizing themes (Step 3). This analysis technique identified clear themes, with the vast majority of young people perceiving educational impacts in three areas. In light of this broad consensus, a further step used the strategy outlined by MacPhail and Campbell (2001), focusing additionally on nonnormative responses (Step 4). Having mapped a thematic network, we reexamined the original data within this framework of consensus and nonnormative themes (Step 5). Finally, emerging themes were discussed with community groups and nongovernmental organizations during the analysis process. Interrater reliability for qualitative coding across each theme ranged from 89% to 96%, demonstrating a high level of consistency although sometimes "packaged" differently. Discrepancies were resolved with joint meetings.

*Quantitative analyses.* Having identified clear normative and nonnormative themes from the qualitative data, we wished to use quantitative analysis in order to understand further the patterns emerging between themes and sociodemographic characteristics of the sample. In particular, we aimed to identify whether educational experiences were affected more amongst adolescents who were living within AIDS-affected household, households affected by other sickness, or healthy households. Once established, we further interrogated associations by testing whether they existed independently of (1) sociodemographic characteristics and (2) extent of work conducted by the adolescent. In order to do this, we created three variables that had been generated by the three normative themes emerging from the qualitative data on school outcomes (i.e., "missing school in order to care," "hungry at school," and "unable to concentrate at school") within SPSS v.16. Participants who identified a theme in their qualitative interview were coded in the quantitative data set as experiencing these aspects of educational disadvantage. Numbers of participants identifying nonnormative themes were too small for multiple regression

analysis but are included in the qualitative results section. Differences between household sickness groups (AIDS-sick, other-sick, healthy home) on school outcomes and sociodemographic characteristics (age, gender, urban/rural, household size, living with parents) were assessed using independent sample *t* tests, chi-square tests and one-way ANOVAs. Associations between sociodemographic factors and school outcomes were also examined; sociodemographic factors that were associated with each outcome at  $p < .20$  level were identified as potential cofactors for multivariate models (Hosmer & Lemeshow, 1989). Qualitative literature on Young Carers suggests that the extent of time children spend in care work may be an important additional factor in determining young people's access to education (Becker, 2005; Robson, 2000; Skovdal et al., 2009). We tested whether this was an independent predictor of missing school, being hungry at school, and lack of concentration at school. We tested associations between being in a home with AIDS-sickness or other-sickness and time spent in care work per day, and also tested whether amount of work was associated with sociodemographic variables.

Multiple linear regression analyses were used to assess associations between household sickness status with each identified educational outcome. Three models are shown for each outcome. The unadjusted models show univariate associations between household sickness category and educational outcome. The first set of adjusted multivariate models control additionally for sociodemographic cofactors, and the final set of adjusted multivariate models control for both sociodemographic cofactors and the extent of young person's work in the home. All tests were two-tailed and significance was set at the  $p < .01$  level because of the number of comparisons made.

## Findings

### *Qualitative Themes*

Responses to open-ended questions elicited three major (normative) themes, identified mostly among the group of adolescents in sick homes; (1) missing school or dropping out of school in order to care for unwell adults, (2) hunger at school due to household-level poverty, and (3) inability to concentrate due to worry about the sick person. Three minor (nonnormative) themes also emerged, which were mentioned by fewer participants; (4) pride in regular school attendance or school achievement, (5) school as a refuge and coping mechanism from being a young carer, and (6) complex dynamics of peer support and peer stigma at school.

### *Major Themes: Missing or Dropping Out of School to Care*

In homes with an AIDS-sick member, 32% of adolescents reported that they were missing school or had dropped out of school in order to care for the unwell person (a further 3% reported missing school for other reasons, such as their own illness, pregnancy, or exclusion). Seventeen percent of adolescents in other-sick homes reported missing school to care, with 5% missing school for other reasons, and 2% of adolescents in healthy homes reported missing school for noncaring reasons ( $p < .001$ ).

The decision to miss or leave school was usually presented by young people as a “forced choice”—that is, that they felt a strong sense of moral obligation to prioritize care of the unwell person:

Yes, sometimes I don't go to school. I decide not to leave my mother alone. I look after her when she is sick. I don't want to lose my mother. (girl, 14, urban)

Although for a minority, the need to provide care was explicitly out of their control:

I don't know what is happening in my life because when my mother is sick, I don't go to school. I have to look after her and my little brothers and sisters. (Boy, 17, urban)

Specific situations in which adolescents repeatedly took time off school included accompanying adults for emergency admissions to hospital:

When she is in pain I call the ambulance. We go together to the hospital, then I don't go to school until she comes back. I take care of my mother, always, when she needs me to help. (Girl, 10 urban)

They also attended hospital and clinic appointments in order to fetch medication or to queue for the sick person (it is common in sub-Saharan Africa to have to queue for many hours, even for set appointments).

I don't go to school. I go with him and queue for him in the day hospital because he cannot manage to stand. (Girl, 17, urban)

Many participants also provided care at home, including washing, medical care, intimate care (such as bathing the sick person) and sibling care. For most,

missing school was explicitly linked to caregivers' sickness "I used to miss school when my mother was sick but she died" (Boy, 10, urban).

Adolescents identified specific needs for home-based care support: "I need someone to look after my grandmother during the week" (Girl, 14, urban). For many, the support needs were multiple, and adolescents expressed the wish that their caregiver would be healthy enough to provide care for the family:

I don't go to school. I clean the house and I give her treatment. I need someone who will look after my grandmother. I need medicines for my grandmother so that she can be better, do job by herself. She can cook for us like before. (Boy, 10, rural)

### *Attending School but Hungry*

In AIDS-affected households, 22% of adolescents reported that they were constantly hungry at school, with 10% of adolescents in other-sick households and 1% in healthy households ( $p < .001$ ).

I go to school without food because we only have very little money to buy everything that is needed. So I feel not right and I can't focus. (Girl, 19, urban)

Lack of school lunch particularly seemed to affect young carers in terms of social isolation and difference from other students:

At school when other scholars are eating I just fold my arms, or I ask them for food because we don't have money to buy food now that my mother cannot work. (Girl, 13, rural)

Since my mother is sick I don't bring nothing at school. I eat nothing. I just drink water during the lunch break. (Girl, 11, urban)

A smaller number of adolescents reported that poverty induced by parental sickness and death meant that they were unable to attend school. Notably, the introduction in South Africa of no-fees schools in high-deprivation areas (in 2006) has resulted in greater access to school for young people. However, some lacked transport costs or were unable to continue schooling due to extreme poverty.

My school is far away. I was using the minibus-taxi. There is no money now. (Girl, 16, urban)

I dropped out of school. I don't have a uniform and at school I was always hungry. My father passed away. My mother does not work. I liked school but there was no-one who could help me. (Boy, 12, rural)

For participants who had finished school, however, poverty-related lack of access to higher education was common:

I passed my Grade 12 last year and now my family is suffering. I didn't have enough money to go to varsity. (Girl, 19, rural)

### *Disrupted Concentration*

In AIDS-affected households, 42% of adolescents reported that concentration at school was difficult, with 33% in other-sick households and none in healthy homes ( $p < .001$ ).

There are times I can't hear clearly because I think about her, how she is doing, whether she is eating her tablets . . . (Boy, 20, rural)

Other young people felt they *shouldn't* be concentrating at school when they were needed at home:

I don't feel OK the whole day in my class. When I leave my parents sick I ask permission to go back home. I decide not to go to school because I don't concentrate—I think of them. (Girl, 10, urban)

Young carers also have specific concerns about care needs; “what she is doing, what she is eating, who is staying with her” (Boy, 12, urban), or fears that the patient will die while they are at school: “I don't concentrate at school. I am worried about my mother. She looks as if she is going to die like my father” (Boy, 14, urban).

### *Minor Themes: Maintaining School Attendance and Achievement*

A number of young people reported with clear pride that they attended regularly or did well at school:

At school I don't skip. I come every day and help my grandma after school. I do my work at school and at home. (Girl, 10, urban)

Sometimes attendance was maintained despite severe distress "my mind just goes away . . . my marks have dropped, but I never miss school" (Girl, 16, rural) and participants clearly identified their future-orientation as motivation for perseverance:

I am concerned about my family at school. But I think about the future. I want to be a lawyer one day so I focus on my studies. (Boy, 18, rural)

Although for some, their ability to attend school was due to the burden of care being undertaken by other young people in the home: "I go to school because my siblings are helping him" (Girl, 15, rural).

A small group of participants in sick homes reported adaptive coping strategies to ensure that their schoolwork was maintained, such as catching up on homework during free periods. Overall, young people expressed a perception of their own education as vitally important in improving their lives and those of their families:

I wish that I can go on with my education and develop myself and make changes in my life so that I can support my parents and family. (Girl, 17, rural)

Many of these responses also suggested that young people are using school as an escape from or as a coping mechanism for their caring responsibilities:

Because of my teachers and friends at school I don't feel the pain. (Girl, 19, rural)

At school I am happy. I think the school makes me forget about everything. (Girl, 18, rural)

I feel happy at school because she (my mother) is not in front of me. If she was there I would be feeling very bad. (Girl, 12, rural)

A small number of adolescents also reported that they appreciated the health information provided in school, and used this to improve their caring capacity:

At school I get information about HIV/AIDS now I listen carefully so that I can help my mother as she is sick. I take in every bit of information about HIV and I will use it to teach my family to take care of my sick mom. (Girl, 15, rural)

For some adolescents, caregiver support for education was an important part of their continued attendance, and a small number described deceased parents as emphasizing the need to continue schooling:

I go to school every day, even if we are finishing exams. Before she died my mother said I must go to school. (Boy, 10, rural)

### *Socialization and School*

Socialization and the building of friendships are an important part of educational goals. Young carers reported very mixed experiences of social support from peers. Mostly, they received positive support from school friends, including emotional and material support (clothes and food).

My friends give me support and love. They don't isolate me because of I come from poor home. (Boy, 17, rural)

However, responses also suggested a potentially difficult dynamic in peer friendships:

I don't bring nothing to school. I depend on my friends to share their lunch if they're willing to give me. If they're not then I don't eat. (Boy, 14, rural)

Some experienced stigma or bullying as a result of familial illness:

My friends at school laugh at me when they talk about me living with a sick person. (Boy, 11, rural)

My friends laugh at me as my mother is sick and they also gossip about me. I feel not right about that in my life. (Girl, 10, rural)

And for some adolescents, accepting support from peers was directly connected to increased stigmatization:

Some of them (friends) they want to help me but it is too hard to take their help because they will make jokes about me and my family. (Boy, 19, rural)

## Quantitative Analyses

### *Participant Characteristics (Tables 1 and 2)*

The mean age of participants was 13.9 years. There were no group differences on age, gender, urban/rural location, or on proportion of adolescents living with both parents. Participants in healthy homes lived in smaller households than those in homes affected by sickness ( $p < .001$ ). Young people in homes with an AIDS-sick person did a mean of 2.13 hours of care work per day, compared to 1.47 hours among those living with an other-sick person and 1.26 hours among those in healthy families ( $p < .001$ ). We categorized participants according to whether they described any of the three primary educational themes (missing or dropping out of school, hunger at school, and problems concentrating at school). Multivariate analyses (controlling for sociodemographic cofactors and extent of care work per day) compared participants living in AIDS-affected homes to those living in other-sick homes and those in healthy homes on these outcomes.

*Sociodemographic cofactors.* Table 2 shows associations between sociodemographic factors, time spent caring, and educational outcomes. Increased age was positively correlated with missing or dropping out of school ( $p < .001$ ) but not with hunger at school or problems concentrating at school. Gender, household size, and living with both parents were not associated with any of these educational outcomes. Adolescents living in urban areas were more likely to report hunger at school compared to those in rural areas (respectively, 14% vs. 7%;  $p < .001$ ), but those in rural areas were more likely to report problems concentrating at school (46% vs. 30%,  $p < .001$ ). The amount of care work that children and adolescents undertook per day was positively correlated with missing or dropping out of school, hunger at school, and having problems concentrating at school (all  $p < .001$ ).

### *Educational Outcomes When Controlling for (1) Sociodemographic Outcomes and (2) Sociodemographic Outcomes Including Hours of Work at Home (Table 3)*

*Missing/dropping out of school.* When controlling for sociodemographic cofactors (age, gender, number of people in the home, living with both parents, and living in an urban area), living in a home with an AIDS-sick person was significantly related to missing or dropping out of school ( $\beta = .320$ ,  $p < .001$ ). Living in a home with other sickness was also significantly related to missing or dropping out of school although this effect was less than that of living in a home with an AIDS-sick person ( $\beta = .145$ ,  $p < .001$ ). In the model additionally



**Table 1.** Differences Between Groups on Demographic Variables

	Adolescents in homes with AIDS-sickness ( <i>n</i> = 212) <sup>a</sup>	Adolescents in other-sick homes ( <i>n</i> = 140)	Adolescents in healthy homes ( <i>n</i> = 247)	<i>p</i> value <sup>b</sup>
Sociodemographic characteristics				
Age (mean, <i>SD</i> )	13.9 (2.9)	13.9 (2.8)	13.9 (2.0)	<i>ns</i>
Female (%)	64.9	58.6	56.2	<i>ns</i>
Household size (mean, <i>SD</i> ) <sup>2</sup>	5.4 (1.9)	5.5 (2.1)	4.6 (1.6)	<.001
Living with both parents (%)	43.4	32.2	43.5	<.03)
Urban—overall sample (%)	58	57	52	<i>ns</i>
Potential explanatory factor				
Hours worked in the home per day (mean hours, <i>SD</i> )	2.13 (2.4)	1.47 (2.2)	1.26 (1.5)	<.001

a. Number of cases overall reduced due to children where familial sickness could not be classified (*n* = 76).

b. *p* value associated with one-way ANOVA or chi-square test.

**Table 2.** Associations Between Demographic Factors, Time Caring and Educational Outcomes<sup>a</sup>

	Missing/ dropping out of school	<i>p</i>	Hunger at school	<i>p</i>	Problems concentrating at school	<i>p</i>
Age	.177	<.001	.052	<i>ns</i> ( <i>p</i> < .141)	.086	<i>ns</i> ( <i>p</i> < .05)
Gender (%)		<i>ns</i> ( <i>p</i> < .44)		<i>ns</i> ( <i>p</i> < .56)		<i>ns</i> ( <i>p</i> < .33)
Male	21.4		10.2		34.1	
Female	23.9		11.2		38.4	
Household size	-.017	<i>ns</i> ( <i>p</i> < .63)	.00	<i>ns</i> ( <i>p</i> < .86)	-.04	<i>ns</i> ( <i>p</i> < .42)
Living with both parents (%)		<i>ns</i> ( <i>p</i> < .78)		<i>ns</i> ( <i>p</i> < .98)		<i>ns</i> ( <i>p</i> < .61)
Yes	22.5		11.8		35.7	
No	23.4		10.1		38.0	
Urban (%)		<i>ns</i> ( <i>p</i> < .15)		<.001		<.001
Urban	24.8		13.6		29.9	
Rural	20.3		7.2		46.4	
Hours of work in the home per day	.162	<.001	.142	<.001	.193	<.001

a. *p* values associated with independent sample *t* test or bivariate associations.

**Table 3.** Multivariate Associations Between Living in a Home With an AIDS-Sick Person or Other-Sick Home and Educational Outcomes, With Two Adjusted Models: (1) Controlling for Sociodemographic Cofactors and (2) Additionally Controlling for Hours per Day of Care Work<sup>a</sup>

	Missing/dropped out of school <sup>b</sup>		Hunger at school <sup>b</sup>		Problems concentrating at school <sup>b</sup>				
	Adjusted model with hours of work		Adjusted model with hours of work		Adjusted model with hours of work				
	Unadjusted Model	Adjusted Model	Unadjusted Model	Adjusted Model	Unadjusted Model	Adjusted Model			
Adolescents in homes with an AIDS-sick person	.328**	.320**	.293**	.201**	.209**	.206**	.250**	.166**	.165*
Adolescents in other-sick homes	.148**	.145**	.137**	.076*	.083*	.083*	.089	.082	.093
R <sup>2</sup>	.117	.135	.159	.044	.046	.066	.127	.219	.055
F-change		17.63**	18.52**		5.47**	6.87**		3.76**	4.31**

a. Comparison group were adolescents living in healthy homes.

b. All adjusted models control for age, gender, no. of people in home, living with both parents, urban or rural areas.

\* Denotes significance at the .05 level. \*\* Denotes significance at the .01 level.

controlling for hours of adolescent work per day, the effect of living in a home with an AIDS-sick person was reduced but remained highly significant ( $\beta = .293$ ,  $p < .001$ ).

*Hunger at school.* When controlling for sociodemographic cofactors, living in a home with an AIDS-sick person was significantly related to adolescents reporting hunger at school ( $\beta = .209$ ,  $p < .001$ ). Living in a home with other sickness was moderately related to hunger at school ( $\beta = .083$ ,  $p < .05$ ). The model additionally controlling for hours of work per day did not reduce the effect of living in an AIDS-affected or other-sick home on hunger.

*Problems concentrating at school.* When controlling for sociodemographic cofactors, living in a home with an AIDS-sick person was significantly related to problems concentrating at school ( $\beta = .166$ ,  $p < .001$ ). Living in a home with other sickness was not associated with problems concentrating in either the unadjusted or adjusted models. The model additionally controlling for hours of work per day did not reduce the effect of living in a home with an AIDS-sick person on concentration problems.

## Discussion

This study aimed to identify and assess the effects of parental sickness and being a young carer on the educational access of a group of adolescents in South Africa. Based on open-ended questions, participants identified three major themes: missing school, hunger at school, and difficulty in concentrating. Smaller numbers of adolescents reported positive experiences of school and school as a refuge from distressing home circumstances.

Quantitative findings provide evidence that adolescents living in a household with AIDS-sickness are more likely to be missing or have dropped out of school, be hungry at school, and have problems concentrating at school than those in healthy homes. These associations remained when controlling for sociodemographic cofactors such as age, gender, location, and household composition. Adolescents living in homes with other (non-AIDS-related) sickness were more likely to be missing/dropping out of school, and moderately more likely to be hungry at school, but did not have more problems concentrating at school than those in healthy homes.

We then examined whether the amount of work that participants did in the home was a cofactor of these educational outcomes. Hours of care work in the home per day was significantly associated with being in a home with an AIDS-sick person and with missing school and problems concentrating at school. In multivariate models, the effect of hours of work per day was associated with missing school ( $\beta = .147$ ,  $p < .001$ ), hunger at school ( $\beta = .095$ ,  $p = .01$ ) and having problems concentrating at school ( $\beta = .132$ ,  $p = .004$ ).

However, amount of hours doing housework did not fully account for the association between being in a home with an AIDS-sick person and educational problems.

This is the first known data comparing educational outcomes for adolescents living in homes with an AIDS-sick person to relevant controls. It used qualitative, participant-led methods to identify recurring themes and then tested them quantitatively. Findings showed adolescents in homes with AIDS-sick people to be particularly vulnerable to educational challenges. We can only speculate causal mechanisms for extreme vulnerabilities in AIDS-affected homes, which may include the effects of having a parent or caregiver experience chronic, intermittent, and debilitating AIDS-illness; reduced household resources due to increasing medical costs resulting in inadequate funds to support school expenses; and (where antiretroviral medication is not accessed) the terminal nature of the disease (Booyesen, 2002). Concentration problems have been reported in a number of qualitative studies of AIDS-orphaned and AIDS-affected children (e.g., Cluver & Gardner, 2007), and are often related to fears that the sick person at home will die. This worry may be more pervasive (and more realistic) for young people in AIDS-affected homes than in homes with other sickness.

It is likely that the negative educational impacts identified by adolescents in this study are linked to poorer long-term educational outcomes. There is extensive evidence that missing school days or dropping out of school is associated with lower chances of completing basic schooling, and might thus lead to lower socioeconomic status as adults (Anderson, Case, & Lam, 2001). Evidence from Kenya shows undernutrition or hunger at school to be directly associated with poorer academic performance (Mukudi, 2003), and undernutrition has been widely shown to negatively affect cognitive development (Gorman, 1995). Anxiety-related concentration difficulties have been linked to underachievement among bereaved adolescents in U.K. studies (Abdelnoor & Hollins, 2004).

Findings from analysis of open-ended questions also suggest that our participants placed high value on obtaining an education. Where young people had left school or were missing school in order to care, this was presented as a competing obligation to that of attending school, and one that took priority only due to the immediate and often desperate needs of the unwell adult. Also notable was participants' perseverance: 16% of all adolescents in sick households continued to attend school despite lacking food at school, and some despite also being exposed to ridicule for their obvious poverty.

These findings may suggest another interpretation of existing literature on orphanhood. Studies in South Africa and other parts of sub-Saharan Africa have shown that orphaned children are less likely to attend school

(Campbell, Handa, Moroni, Odongo, & Palermo, 2008; Case & Ardington, 2005; Mishra, Arnold, Otieno, Cross, & Hong, 2005) and less likely to complete primary school (Operario, Pettifor, Cluver, MacPhail, & Rees, 2008), but it is possible that these educational deficits experienced by orphans may actually reflect a longer cycle of difficulties that begin with parental illness. If so, the findings of this study would have relevance to the many policies that currently target orphans for educational support. It is possible that, by providing support before parental death, difficulties experienced by orphans may be reduced. Another potential intervention is suggested by a recent Kenyan study of HIV+ adults, which found that parental initiation on antiretroviral medication resulted in a 20-hr average weekly increase of school attendance among their children (Graff Zivin, Thirumurthy, & Goldstein, 2006).

Many of the adolescents interviewed in this study faced a dilemma. While placing high value on obtaining an education, they perceived a compelling moral obligation—sometimes presented as a family duty—to assist a sick caregiver. Some participants expressed a sense of pride in being able to help their families in a time of need, while others viewed their role in the family support network as a necessity rather than a choice. If we are to develop contextually appropriate responses to the needs of this group of young people, it may be helpful to use the concept of “forced choices.” This framework recognizes that adolescents are participants in the decision-making about the extent of care that they provide but that the decisions that they make are severely constrained by extreme need and lack of material and health care resources. This study clearly demonstrates that the “forced choices” that adolescents make are affecting negatively on their access to education.

This study also suggests that Bronfenbrenner’s ecological framework may be a helpful theoretical approach to the educational challenges experienced by “Young Carers.” The impact of adult caregivers’ AIDS-sickness, combined with health care resource shortages and extreme poverty, contribute to limited educational access for adolescents. But this also suggests that support for young carers—in spheres such as poverty reduction and health care support, could potentially buffer these risks. Additionally, participants identified school itself as a supportive and buffering environment to reduce the psychosocial impacts of the stressor of caregiver sickness. In devising policy responses, it may be helpful to consider a recent study by Freeman and Nkomo, where prospective families were surveyed regarding their willingness to incorporate orphaned children into their households. The majority of respondents perceived that their family obligation was to take on orphaned relatives, but that “help” (material, educational, and from a supportive, trained person) was

essential in order to facilitate this (Freeman & Nkomo, 2006a, 2006b). The findings of this study tentatively suggest particular forms of support that may be helpful for adolescents in AIDS-affected households, such as assistance in supervising the unwell person; assistance with queuing for medication at health care facilities; further expansion of the existing National School Nutrition Program that provides free meals at schools; and psychosocial support for young carers. However, this is an exploratory study, and further research is necessary in order to inform evidence-based policy making.

This study has a number of limitations. First, we cannot be sure that this was a representative sample of young people in sick homes. However, community-based sampling methods allowed us to include participants who were missing or not attending school and who may have been omitted from a school-based study or a study recruiting through services. The cross-sectional nature of the research precludes determination of causal mechanisms—future research could valuably test the impacts of worsening or lessening parental illness on adolescents' education.

HIV-testing and disclosure rates in South Africa are low, and we were unable to collect reliable clinical data on cause of illness of household members. However, the verbal autopsy method has been validated in South Africa, and we used a conservative threshold of 3+ AIDS-defining symptoms. It was unknown whether household members in the other-sick and healthy groups may have been HIV+ but not AIDS-symptomatic. However, illness among families of control groups would tend to have the effect of reducing group differences, and yet differences remained highly significant. It is also important to consider the possible influence of researcher bias in the qualitative stage of the study. All attempts to reduce personal bias were made by designing the protocol in collaboration with the Teen Advisory Group and by discussing analysis with community groups.

The study also has strengths: to our knowledge it is the largest study to date of young carers in sub-Saharan Africa, and the first to provide quantitative data on the impacts of familial AIDS-illness and extent of caring tasks on education. The phenomenological approach was used in light of the lack of available data, and showed clear themes in young people's experiences, which were supported by quantitative analyses.

In conclusion, this exploratory study aimed to cast some initial light on the educational experiences of adolescents living in sick households in South Africa. Findings showed clear themes of high levels of missing school by young people, anxiety and worry causing concentration problems, and hunger at school. They also showed commitment to school, support from peers,

and perceptions of school as both a respite and a route to future success. It is essential that future research determines risk and protective factors for access to education, in order to inform policy and interventions.

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